Ad9/990

Advanced Cancer:
Living Each Day

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

HE 20.3152:

READEX FICHE best copy available

Advanced Cancer: Living Each Day

NIH Publication No. 91-856
Revised August 1987

National Cancer Institute
Bethesda, Maryland 20892

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

Contents

Introduction 1

Living With Advanced Cancer 2
How Others Have Coped With Advanced Cancer 2
What You Can Do 5
Sharing Your Thoughts 6
If You're Alone 7
Intimacy 7
Living Each Day 9

Common Concerns 10
Facing the Unknown 10
Dealing With Loneliness and Isolation 12
Maintaining Self-Respect 12
The Grieving Process 13
Managing Pain 13
Emotions and Pain 14
A Theory About Dying 15

The People in Your Life 18
How Children React 18
Partners 20

Options for Care 22
The Hospice Concept of Care 22
Making Treatment Decisions 22

Practical Concerns 24

Resources 27

Introduction

Advanced cancer affects everyone whose life it touches—the patient, family, and friends. Dealing with the changes and the problems caused by a terminal disease and facing the future are difficult challenges.

This booklet aims to help make living with advanced disease easier by providing practical information and by addressing questions that are often asked. It does not attempt to minimize the seriousness of having advanced cancer or deny its difficulty.

"Living Each Day" is based on the most current written information, and on interviews with advanced cancer patients and those close to them. Throughout the booklet, several messages and suggestions are stressed:

- Try to live each day as fully and normally as possible.
- Many of your concerns can be eased with medical skill, emotional support, knowledge, faith, and love.
- A decision to make the most of the time available can help you help yourself live with advanced cancer.

It is possible to live with a sense of purpose and the hope that good relationships will continue, that family, friends, and caregivers will be available to provide the support you need, and that each day will offer its measure of happiness.

Not everyone will want all the information in this booklet, nor will all find it suited to their needs. Perhaps parts of it will spark a new thought, relieve anxiety, or help solve certain problems for you. Even at this difficult time, there are many things that can be done to help you and your loved ones.

Living With Advanced Cancer

Few people like to think about dying. We all know that death will come, but most of us spend little time thinking about it. Many of us think of dying as something that happens to other people, believing that we will live on and on.

While this belief may be comforting, it is no longer useful when you have weeks or months—not years—to live. Approaching death often requires changing how we look at life and what we value. You will need time to think about death and adapt to its approach.

One patient with advanced cancer expressed his philosophy about dying this way:

> *The death rate for any generation is 100 percent. We all die. However, I know what will probably kill me, while most people don't. We have no guarantee of how long we will live. But I believe it is truly the quality of life, not the quantity, that is most important.*

There are no right or wrong ways to face the end of life. You need to do what is right for you. Many people with a terminal illness have been able to find peace of mind by coming to terms with their emotions and beliefs about their lives, and about dying. You may be able to do this too, in your own way and at your own pace.

How Others Have Coped With Advanced Cancer

There are probably as many ways to cope with advanced cancer as there are people trying to do so. Each of us is unique, and we each find our own way to live and to die. Still, we have many feelings in common and may approach the knowledge that our time is limited in similar ways.

Many people find it easier to concentrate on the present, and do not focus on the distant future. They think of the future as the end of each day, and live one day at a time. As one patient explained,

> *Before this happened I had a 5 year plan, a 10 year plan, even a 20 year plan. No more . . . what I realized was that I could only die in the future, but I was alive right now and I would always be alive in the here and now.*

Others find it more helpful to plan ahead—within limits—days, a month, 6 months, possibly a year. They find that it reaffirms, to themselves and to others, that there are still things they want to do. Their plans may be general, such as enjoying family and social relationships and talking about their thoughts and feelings, or specific, such as reading a certain book, or finishing some needlepoint.

Some view having cancer as a challenge to be met or a battle to be fought. They think of each day they survive as a victory. One woman expressed her outlook this way:

> *I get satisfaction by being engaged in the fight. It's me and my doctors against cancer, and we know we might not win in the end; but by God, we're going to give it a run for its money.*

Others cope by rethinking what is important in their life and what is not. "Disease rearranges your values, and you cast off things. You reduce the trivia to a minimum, you simplify life. . . ."

Still others may not be able to accept the seriousness of the situation. They may deny the fact that they are dying until their final moments.

Many people are emotionally overwhelmed when they first learn their diagnosis. With time, their reactions may change to acceptance and a desire to do as much as possible in the time that remains.

Others, instead of accepting, lose their ability to cope and their will to live. This does not have to happen. You can choose the way you wish to face each day. Even if you are very ill, you may still have physical and emotional reserves. Deciding to call on these reserves can help revive your spirits and your will to live.

We are all born with the will to live. Exactly what influence this force has in curing disease—especially cancer—has long been debated, but there is little argument that a strong desire to live can enhance the quality of life. Those who are determined to live fight harder and sometimes seem to do better.

There are many people with advanced cancer who have lived far longer than expected. A positive attitude about the value of life, along with a combination of hope, endurance, willpower, and courage, are common characteristics of such people. When asked to explain how they have managed, these people often give answers such as "I'm needed too much at work" or "I can't die until my grandchild is born" or "I need to help my daughter." They do not seem to want to give up or retreat from living. A keen interest in daily events appears to keep them from giving up.

Others have approached illness and dying from a different point of view. They believe that life is so precious, under any conditions, that they simply will not let it go. This intense need to go on may be present with or without the help of family, friends, concerned caregivers, or effective treatment. It may even exist without any apparent sources of encouragement. These people seem to generate their own hope and keep going through sheer willpower.

This does not mean that a positive mental attitude will necessarily lengthen your life. Neither does it mean that you are inadequate if you are sick and not getting better. But trying to emphasize the positive aspects of your life can add meaning, purpose, and comfort to the time remaining.

What You Can Do

Accepting responsibility is one way to help yourself. By actively participating in daily activities with your family and friends and in your care, you say "I care about myself."

Set goals for yourself that are realistic so you do not become discouraged. Find out what caregivers, friends, and family are doing for you and what you can do to help yourself. Let them know what you need; this may include their presence, concern, and honesty.

You can also accept responsibility for your frame of mind. Set the tone for those around you. As one patient said, "You have to do this because no one knows how you want to be treated, and they may be waiting for a cue. No one else will talk about it unless you do. . . ."

Your caregivers may recommend a regular exercise program (even if you are in bed most of the time), medications to be taken at certain times, and nutritious food. These measures or others prescribed for you may, at times, seem unimportant in the face of declining health, but they will help you to keep your strength and your independence for as long as possible. Working with your caregivers and family can help you maintain a sense of control, purpose, and hope. Encouraging honest and open communication will help you to live the way you want to, and it will let others know how you want to be treated.

Living with serious illness can be very discouraging. You will have good times and bad times too, and your ability to deal with

these changes may vary. In the morning you may feel down, but by the afternoon you may feel much better. On one day you may have little energy, but on another your mood and spirit may rebound. During a bad time, try to remember the good moments and remind yourself that there can be more good times ahead.

Sharing Your Thoughts

Many people with cancer have found it easier to live with their problems by sharing them with someone. The weight of your problems may be lightened just by talking them over with family members or a close friend. They may even think of a way of dealing with a problem that has not occurred to you.

You may find this kind of sharing difficult, and sometimes it may also be hard for family members or friends. If this is the case, you might want to talk to a member of your medical team or with someone who is professionally trained in counseling, such as a nurse, social worker, psychologist, a member of the clergy, or other community and hospital caregivers. Many people have found support by attending self-help groups where people meet to share common concerns. They say sharing and learning from each other gives them strength and reassurance.

Sometimes people prefer to work through their feelings alone, but it often helps to share. The emotions and thoughts that go along with advanced cancer are understandable and expected, and it is not necessary to hide them. Letting your feelings out can be a great release.

If You're Alone

It may be very hard to keep up your spirits and be positive if you live alone. Loneliness is not easy to deal with at any time and may be especially difficult during illness. Many people have found this time less lonely with the help of an adopted family, friends, a volunteer, or a member of the clergy.

If you need to rely on yourself for encouragement, try to cheer yourself on. It may be very hard to do, but it's far from impossible. There are people who have learned to cope by thinking positively, helping others, and remaining as active as possible. Focusing on small pleasures—a delicious meal, a good book, a beautiful sunrise—has helped many people.

Intimacy

Advanced cancer affects all aspects of life including sexuality. You may find yourself unable or unwilling to express yourself sexually as you did before because of physical changes and emotional concerns. This does not mean, however, you must deny sexual needs and desires. There are many ways to show love and to find satisfaction.

Open, honest communication is the key. Being willing to reexamine your attitudes about intimacy will help you and your partner maintain the closeness, warmth, and sense of belonging generated in a loving relationship. Physical satisfaction can be

sought in a variety of ways and may or may not include intercourse. Touching, kissing, stroking, and holding can also bring great comfort and pleasure.

Sexual problems may stem from feelings about your medical condition or treatment, rather than the condition or treatment itself. With patience and communication between partners, many of these problems can be solved. An understanding that intimacy may not be the same as it was before can prevent unrealistic expectations and relieve some of the self-consciousness you or your partner may be feeling.

Don't be afraid to seek help or advice. Ask—you are entitled to all the information you need or want. You may wish to seek counseling, and your doctor, nurse, social worker, or patient representative in the hospital may be able to guide you to a professional in this area. The library has many books on sexuality and you may find some of them helpful.

Living Each Day

Choose small goals and constructive ways to use your time, instead of dwelling on your illness. Sometimes, asking yourself "What do I cherish?" or "What is important to me right now?" can help you focus on meaningful goals. Try thinking of the needs of your family and others close to you. You may enjoy looking through and arranging family albums, scrapbooks, or hobby collections. Pets still need to be cared for and plants watered.

Some people keep a daily journal of their feelings and experiences. You may want to try this, to share with someone close to you now, or to leave them as a remembrance. Try directing your energy into living each day as it comes, and make each day count for what you can put into it.

The will to live is a part of each one of us. Some people think of it as a small flame that we carry within ourselves. For many, it is a source of strength that can make it possible to look forward with hope to each day.

Common Concerns

Some say it is not death we fear, but the days, weeks, or months that precede it. Many of us are afraid there will be pain during this time, and we wonder if we will become a burden. We may think about the unknown, about isolation and abandonment, and that life will be over before we are ready.

Family and friends can help you to work out concerns and control fear—by listening when you want to talk and by being honest and sensitive to your feelings. But they may have fears, too. They need to know about your disease, what they can and cannot do for you, and what to expect.

Knowledge and understanding may help you gain perspective on these concerns. If there is something you want to know from a member of your health care team, ask. Let your doctors, nurses, and others know what information you want and need. It is your right to receive answers, even to the most direct questions about your prognosis.

It may be a good idea to include those close to you in talks with your doctor. Talking directly to your caregivers may ease your family's and friends' concerns, give them a clearer understanding of how they can help you, and help them feel less helpless in a difficult situation. The value of honest communications for all those involved cannot be stressed too much.

Facing the Unknown

Many people with advanced cancer wonder what experiences they will miss in life, what the moment of death will be like, and what their fate will be after death. They wonder, too, what will become of their family and friends, and how these people and others will react to their death.

It may help you to talk about these thoughts with a person you feel comfortable with. While some questions can be answered—immediately or in time—others have no answer. A definite answer to practical, spiritual, and religious issues may not be possible, but discussing them—with a friend, partner, member of the clergy, or caregiver—may help you to explore these questions and feel less alone with them.

Dealing With Loneliness and Isolation

As cancer progresses, it disrupts the activities that have made up your daily routine. This can lead to feelings of loneliness and isolation. Sometimes this happens even if you are surrounded by family and friends because they can't share your experience.

One way to minimize these feelings is to try to live as normally as possible. Keep close at hand the things you have always enjoyed—photos, art, magazines, music. Surround yourself with familiar things. Even in the hospital you can wear your own clothes, have your own blanket and pillows, and keep mementos and pictures nearby. You may want to keep up with local or national news, or watch a favorite television program with a friend.

Don't be afraid to call and ask friends and relatives to visit. They may not have contacted you because they don't know what to say or how to act, or are not sure you want visitors. If you do, let them know. At first, you may wish to suggest specific activities—reading aloud, playing cards, watching television—until you and your visitor feel comfortable with each other again.

Despite all your efforts, you may still feel lonely and isolated or feel that your family and friends cannot understand your problems. Some days you may just want to be left alone, and that is okay too. On other days, talking to others with cancer might provide the understanding and companionship you need. You may wish to join a support group for cancer patients. Some of these are listed in the resource section at the back of this booklet. The American Cancer Society, a local hospice, your doctor, a social worker, a visiting nurse, or a member of the clergy may also be able to put you in touch with another person or group that would be right for you.

Maintaining Self-Respect

It can be very hard for you to accept that your body is no longer as strong and reliable as it once was. As cancer progresses, your appearance may change and you may not be as independent as you once were. This may affect your self-respect. If this happens, remember that the qualities that make you a good friend, a loving parent, or a caring mate are still there. One woman with advanced cancer had this to say:

It shouldn't take a fatal diagnosis to . . . find self-awareness, self-concern and self-love. . . . But I'm afraid for most of us it does. I think I've straightened myself out in these areas. In fact, I've discovered . . . that I'm a stronger person than I might have anticipated. I am just a bit gutsier than I thought and I'm delighted to know that.

Even if you are bedridden, you can exercise a degree of independence and initiative. You can maintain control in little ways—setting up a schedule for getting up, shaving, bathing, and resting. (If you can't do these things for yourself, you can let others know when you would like to have help.) Decide for yourself which television programs to watch, which books to read or have read to you, and how long to exercise.

Whether at home or in the hospital, let those caring for you know which foods you prefer, whether you are comfortable, and if there is something you need.

Many people with advanced cancer are not bedridden. You may be able to do things you used to, but in a more limited way. Conserve your strength for those activities you really want to pursue.

Ultimately you will have to let others care for you. Dependence on others is natural when you are not as strong as you once were.

The Grieving Process

Sadness and grief come with the unavoidable losses that occur with advanced cancer and are not unusual reactions. Fortunately, the losses are usually gradual. You may be able to accept the losses and your feelings about them a little more each day.

Dealing with a particular source of sorrow and working through the emotions surrounding it may help you set it aside. Grief about the people and things you must eventually give up does not have to be denied or hidden, but try to balance it with activities and relationships that have meaning for you and bring you happiness.

Managing Pain

Many people with advanced cancer are afraid they will experience physical pain. However, some cancer patients, even those with advanced cancer, do not have any pain at all, or very little.

If pain reaches the point where it disturbs you, it needs to be treated. It can almost always be minimized and often managed so that it does not recur.

The combination of appropriate pain relief methods, the opportunity to make personal and spiritual peace, and someone willing to listen and offer comfort and advice are probably the most potent pain relievers known.

There are many medicines that can be used alone or in combination to relieve your discomfort. Physical therapy and biofeedback, relaxation techniques, and self-hypnosis may also help. Caregivers may be able to help you with these therapies, and you may want to see what the local library has to offer. The librarian can help you or a family member locate books and records on these topics. The level of pain, your willingness to help manage your pain, and the cooperation of caregivers and family will determine which method is best for you.

Your doctor may prescribe narcotics (pain-relieving drugs) for you. When used under proper medical supervision, the chance of addiction to narcotics is small. Most people can stop taking these drugs or decrease the amount of medication taken if their pain can be controlled by other means. If narcotics are the only way to relieve pain, your comfort is more important than the possibility of addiction. If you and your doctor decide narcotics are a proper choice for you, use them as directed.

A booklet on handling pain, *Questions and Answers About Pain Control*, is available from the American Cancer Society. Contact your local ACS office listed in the telephone directory to obtain a copy.

Emotions and Pain

People with advanced cancer may be sad, depressed, angry, scared, or all of these. These are normal reactions when you are very ill and realize you probably won't live as long as you had expected. When your emotions become overwhelming they can make your pain seem more intense. Talking about your feelings may help give you, family, and caregivers guidance about what you need. It can also help to relieve sadness and depression, and may reduce pain. Writing about your emotions in a diary may help too. Occasionally you may feel like kicking or punching a pillow, or screaming and crying. Go ahead and do it.

Personal and spiritual problems may be troubling you as well. These can contribute to pain. You may want to bring up unresolved conflicts that have developed over the years between you and a friend or family member. Approached with kindness and openness, old hurts can possibly be put to rest. At the least, some level of understanding can be established between the two of you along with happier, more peaceful feelings.

Your family or caregivers can arrange for a priest, rabbi, minister, hospital chaplain, or other appropriate person to visit with you. Many people find comfort in expressing and trying to resolve personal spiritual issues.

A Theory About Dying

Each of us must face death and accept it in our own way, answering questions as best we can about the meaning of life, love, suffering, and struggle. We can hope to find some measure of peace, and acceptance of the coming of death. Unfortunately, the journey toward these goals is not easy or steady. And sometimes, it is not possible for us to reach all our goals.

The emotions that many people with advanced disease experience have been examined by trained professionals. One whose theories have become well-known to the public is Dr. Elisabeth Kübler-Ross. You may have heard about the feelings she believes dying people experience. Her work has provided guidance and comfort for many patients and their families, but it is important to remember that her theory is only one perspective on dying.

You may not experience all of the emotions that are discussed here. They are presented to reassure you and those close to you that your reactions are not unusual, but a part of the way we try to make peace with ourselves.

When patients are first told or realize they are dying, they often react with disbelief. It is a common way to cope with an overwhelming situation and can be helpful at first. Eventually, however, you must face reality, and in time many do. One patient explained it this way:

> *The reality of death does not go away by denying it. When you do this you can miss the comfort you get from sharing fears and concerns and missing the sense of well-being you get knowing you have taken care of your loved ones.*

This feeling of "No, not me!" often changes to "Why me?" You may feel angry, resentful, even enraged. These strong emotions need to be expressed if they are to be relieved. This can be a very difficult time for you and those around you. It will help everyone to understand that your anger is not meant for those close to you but for the situation.

People may make all kinds of promises to God or to themselves with the hope of a longer life: "If I can live one more year, I'll go to church every day" or "If I can just live to see my son married, I won't ask for more." It is not unusual at all to do this.

At times you may feel depressed, because you have lost your independence, or because your savings were spent on medical care. You can help yourself at this time by valuing what you have, rather than dwelling on what you cannot change.

As you move closer to death, depression over losses that have already occurred may give way to grief over the friends, family, and life you are going to lose. This grieving should not be discouraged—it must be worked through in order to say a peaceful goodbye.

During this time it will help not to be alone, though you may find yourself gradually needing fewer people around you—perhaps just those you feel especially close to. It may help your family and friends to understand that this type of withdrawal often occurs toward the end of life and it is not due to something they have done or should feel badly about. Conversation may not be necessary, just the reassurance that someone is there for you who cares. Reassurance can be communicated by the presence of another, by holding someone's hand, by a gentle touch.

Not all people facing death are able to find peace and acceptance. However, with time and help you may be able to come to the feeling that you have accepted what must be. At this time you need reassurance, more than ever, that you will not be left alone and all that can be done for your peace and comfort will continue to be done.

The People in Your Life

Family and close friends are a primary source of emotional support for people with advanced cancer. One young woman says, "My husband and friends who love me are like a circle . . . they form a protective shield around me. I don't know what I'd do without them."

Those who are close to you need understanding and consideration as much as you do. Your expectations about what they can and should do for you should be tempered with knowledge about their feelings, abilities, and limitations. They may need time, just as you do, to adjust to your illness, and any feelings of confusion, shock, or anger they may have. Letting them know that you want them close and that you need their support will help them with their own emotions.

How Children React

Children who have a parent with advanced cancer are almost always aware of a great change in their daily lives. Even preschool children sense when something is wrong. They may be frightened by this change or become angry at you for being ill. Others, especially younger children, worry that they might have caused your illness.

Because of these possible reactions it is best to be honest and encourage communication. Try to let your children know that they are allowed to ask questions, and that you will answer them as honestly and thoroughly as you can. Tell your children as much as you think they can understand. Keep in mind that many people tend to underestimate how much children do understand.

You may want to try telling them a little at a time. A partner or relative may be able to help—together you can watch for clues that the children have absorbed as much information as they can at that time.

Children need to know that they are still loved and important, and that they will continue to be cared for. A favorite relative or friend can help by devoting time and attention to a child who needs comforting, affection, and guidance. Perhaps this person can offer to help with homework or attend important school events if you cannot.

Taking the time to listen to a child's triumphs, problems, and fears is important. This holds true for adolescents as well as for younger children. Teenagers are sometimes expected to assume responsibilities that are beyond their maturity. If you can avoid imposing too much responsibility on them, while maintaining a sense that they are important family members and still entitled to their independence, you may be able to keep their problems to a minimum.

If this kind of support is not enough, professional counseling may be necessary. Your doctor, social workers, other community and hospital caregivers, and state or community mental health departments can guide you to a counselor who is right for you and your children.

Partners

Communication is a two-way street between you and your partner. Being honest about the emotions both of you are feeling can help you draw support from each other. Endearments, hugs, and kisses can also bring a sense of comfort and togetherness.

Be realistic about demands on your partner who is, undoubtedly, having a hard time too, and may be feeling guilty about your illness and any time spent away from you. Communication is especially important if you and your partner have been separated by hospitalization for prolonged periods of time. Sometimes in the absence of their partners, patients begin to draw more support and relate more personally to members of their health care team. This pattern of relating may be difficult for partners to adjust to if they no longer feel needed.

Partners need time to meet their own needs, along with those of other family members. If these needs are neglected, your partner will have less energy, cheer, and support to give. Another family member or friend can sit with you for short periods of time while your partner attends to other details of daily life—a shower, a walk, phone calls to friends, or business matters.

The time away will replenish both of you, and give you the opportunity to visit with others. Remember, you didn't spend 24 hours a day with your spouse before your illness. You still have many of the same emotional and personal needs that you did before your illness and may need some time apart. It is better to try to maintain your relationship as it was before, as much as

possible. If you are in the hospital, your doctor and nurses can provide support during the time your partner may be away.

Your partner may not be your only or primary source of emotional support. Sometimes it is a mother or father, brother or sister, or best friend. It may be one of your adult children.

These people have feelings, too, and other responsibilities. Keep demands as realistic as possible and try to keep communication flowing. Express your emotions and let them express theirs if they wish. Well-deserved praise, a hug, kiss, or hand squeeze are not out of place and can provide warmth, good feeling, and renewed energy.

Options for Care

Hospitals and machines that sustain life have become such an accepted part of illness that we sometimes forget there are other places and ways to live with advanced disease and approaching death. Many patients are most comfortable in the hospital, where they feel assured of the care and comfort they need. Others want to remain, or return home, and this kind of care can be arranged with the cooperation of the patient, family, and professional caregivers. Still others may have a hospice organization in their area and may wish to avail themselves of this kind of care. You may want to think about the choices available, and what would be best for you.

The Hospice Concept of Care

Hospices provide specialized care for dying patients and their families. In hospices the primary concern is quality of life, not prolonging life. They stress controlling pain and other symptoms so the patient can remain as alert and as comfortable as possible. Emotional, social, and spiritual health and followup care for the family are important too.

Hospices offer both inpatient and home care. There are free-standing hospices, hospices within a hospital or skilled nursing facility, or at-home care arrangements.

In 1978, the National Hospice Organization (NHO) was established to promote and maintain quality hospice care and to encourage support for patients and family members. For information about NHO or about hospice concepts and practices, contact the National Hospice Organization, 1901 North Moore Street, Suite 901, Arlington, VA 22209, (703) 243-5900.

Making Treatment Decisions

Family, friends, and caregivers may find it hard to accept, but the time may come when continuing to live is no longer a patient's top priority. A patient may opt for experimental drugs and methods, or decide to end treatment. This point may be reached when standard therapy is no longer effective, when the quality of life is no longer acceptable to that person, or at some other time.

Refusing Treatment

It is your right to refuse further treatment. If you make this decision, treatment will be given only to relieve pain and other

symptoms and to keep you as comfortable as possible. If your condition stabilizes, therapy can always be started again. Your doctors will, almost certainly, have recommendations, information, and advice to give you about this course of action, but they cannot act against your wishes.

Many religious groups have issued statements about the decision to end treatment. Most do not oppose such a decision. If you want to know more, ask your priest, rabbi, minister, or other counselor.

Patients' Rights

You have other rights, too. You are entitled to be given complete information about your illness and your prognosis and to withhold that information from others if you wish. You should also be informed about any procedures and treatments that are planned, and how much they will cost.

The American Hospital Association has prepared "A Patient's Bill of Rights." You can get this document from a library, hospital, or directly from the American Hospital Association, 840 North Lakeshore Drive, Chicago, IL 60611, (312) 280-6000.

The Living Will

A Living Will is a legal document that states you do not wish to be kept alive by artificial means or heroic measures. It is a recognized statement of your right to forego treatment and has been upheld in court.

If you sign a Living Will, tell everyone close to you and give them copies. Your health care team and lawyer should also be informed and given copies. This is to ensure that your wishes will be carried out.

You can obtain a copy of the Living Will, in the form preferred by your state, from Concern For Dying (CFD), 250 West 57th Street, New York, NY 10017, (212) 246-6962. Signing a Living Will will not, according to CFD, adversely affect any life insurance policy and will not be interpreted as suicide.

CFD recommends appointing someone who can make binding decisions for you about medical care in the event you can no longer do so (power of attorney). Name a person who knows your views about specific treatments and any religious considerations that need to be taken into account.

Practical Concerns

Careful planning can help to minimize the financial, legal, and emotional difficulties your family and friends may face after your death. However difficult it may be, discussing practical matters now can eliminate many problems. Advice from professional counselors and advisors—lawyers, members of the clergy, funeral directors, insurance company representatives—can help you make decisions that fulfill your requests and help those close to you.

You can help your family and loved ones by gathering copies of records, documents, and instructions they will need. A large envelope can be used to store copies of your important papers. Only photocopies should be placed in the envelope. Originals should be stored in a fireproof place such as a safety deposit box. Be sure to tell one or more people where you keep the envelope. If you cannot gather all these items, list where they can be found. You can use the following form as a guide for collecting your personal records.

Personal Inventory

Name_____ Date_____

Address_____

Date of Birth_____ Place of Birth_____

Social Security Number_____

Next of Kin: Name_____

Address_____

Employer

Address_____

Company Benefits_____

Personal Papers

Item: (Veterans' discharge papers, birth certificate, Living Will) Location:

_____

_____

_____

Insurance

Life: Company (Name and Address)

_____Policy Number _____

Health and Accident: Company

_____Policy Number _____

Automobile: Company

_____Policy Number _____

Other: Company

_____Policy Number _____

Banking Papers

Kind of Account	Bank Name/Address	Account Number
_____	_____	_____
_____	_____	_____
_____	_____	_____

Other Accounts

Type	Where	Account Number
Safety Deposit Box		

Automobiles (Make, Model, Year)

Real Estate Papers

Personal Items of Value

Counselors Who Can Help With My Affairs

Attorney

Banker

Insurance Agent

Doctor

Clergy

Other (Broker, Business Associate, Accountant)

Funeral Arrangements

Special Requests

Resources

Free copies of this booklet and other publications related to cancer are available. Write to the Office of Cancer Communications, National Cancer Institute, Building 31, Room 10A24, Bethesda, MD 20892.

The Cancer Information Service (CIS) of the National Cancer Institute answers questions from the public, cancer patients and families, and health professionals. Trained staff are available to answer your questions about cancer, medical facilities, home care assistance programs, financial aid, emotional counseling, and other services.

By calling the toll-free telephone number

1-800-4-CANCER

you will be connected to the CIS office serving your area. Spanish speaking staff members are also available. You may call CIS as often as you wish. Your calls will be kept confidential. You do not have to give your name if you would rather not.

Other organizations that may be helpful as sources of information and assistance are listed below. The addresses and phone numbers shown are for national headquarters. Look in your telephone book or call the CIS for information about local chapters or units of these organizations.

Other Organizations

American Cancer Society
1599 Clifton Road, NE
Atlanta, GA 30329
(404) 320-3333

A voluntary organization offering a variety of patient services, also involved in cancer education and research. The ACS sponsors:

I Can Cope—addresses the educational and psychological needs of people with cancer.

CanSurmount—"team approach" composed of patient, family member, trained volunteer (also a cancer patient), and health professional. On physician referral, a trained CanSurmount volunteer meets with the patient and family in the hospital and home.

Cancer Care, Inc. and the National Cancer Care Foundation, Inc.
1180 Avenue of the Americas
New York, NY 10036
(212) 221-3300

A voluntary social service agency providing professional counseling and planning to advanced cancer patients and their families.

Leukemia Society of America, Inc.
733 Third Avenue
New York, NY 10017
(212) 573-8484

Supplemental financial assistance and consultation services are offered to cancer patients with leukemia and related disorders.

Make Today Count
101½ South Union Street
Alexandria, VA 22314
(703) 548-9714 or (703) 548-9674

The goal of this organization is to help patients with incurable diseases and their families cope with illness and improve their quality of life.

The Candlelighters Childhood Cancer Foundation
1312 18th Street, N.W.
Suite 200
Washington, DC 20036
(202) 659-5136

A voluntary organization that provides practical information and psychological support for parents of children with cancer.

General References

Kelly, Orville. *Make Today Count*, and *Until Tomorrow Comes*, available from Make Today Count, P.O. Box 222, Osage Beach, MO 65065. These books relate how Orville Kelly reacted to his diagnosis of cancer and his goal to "live each day as fully and completely as possible." His philosophy is to promote honest and open communication between patients, family, and caregivers.

Morra, Marion, and Potts, Eve. *Choices. Realistic Alternatives in Cancer Treatment*, New York, NY; Avon Books; 1987. A comprehensive guide for cancer patients and their families. Sections on different kinds of cancer treatment options including experimental and unproven treatments, coping with pain, questions to ask caregivers, and where to get help.

Rosenbaum, Ernest, M.D. *Living With Cancer*, St. Louis, MO; C.V. Mosby Co.; 1982. Focuses on individual cancer patients and how they have coped with their illnesses. Many first-person accounts of their emotions and thoughts.

Rosenbaum, Ernest, M.D., et al. *A Comprehensive Guide for Cancer Patients and Their Families*, Palo Alto, CA; Bull Publishing Co; 1980. A thorough discussion of the questions and problems faced by cancer patients and their families.

Nutrition Information

American Cancer Society. *Nutrition for Patients Receiving Chemotherapy and Radiation Treatment,* available from local units. Describes the importance of maintaining nutritional intake while receiving chemotherapy and radiation and how these treatments affect caloric needs.

Office of Cancer Communications. *Eating Hints—Recipes and Tips for Better Nutrition During Cancer Treatment,* National Cancer Institute, Building 31, Room 10A24, Bethesda, MD 20892. Includes recipes designed to help you increase protein and caloric intake and suggested ways to stimulate your appetite.

Rosenbaum, Ernest H., M.D., et al. *Nutrition for the Cancer Patient,* Palo Alto, CA; Bull Publishing Co.; 1980. Practical advice about how to maintain weight, and why it's so important for the person with cancer.

Children and Death

Grollman, Earl. *Explaining Death to Children,* Boston; Beacon Press; 1965. No matter how young, children sense the impact of serious illness. This book offers a practical approach for explaining death and dying to them.

Le Shan, Eda. *Learning to Say Goodbye, When a Parent Dies,* New York; Macmillan Publishing Co, Inc.; 1976. Designed to help children through a difficult time.

Moving Toward Death

Duda, Deborah. *A Guide to Dying at Home,* Santa Fe, NM; John Muir Publications; 1982. Practical considerations for seriously ill patients who want to remain at or return home.

Kubler-Ross, Elisabeth. *On Death and Dying.* New York, NY; Macmillan Publishing Co., Inc.; 1969. Discusses the emotions that many dying people experience.

Hospice

Hamilton, Michael, and Reid, Helen, editors. *A Hospice Handbook*, Grand Rapids, MI; Eerdmans Publishing Co; 1980. A guide designed to help the patient and family evaluate if hospice care is an option for them.

Stoddard, Sandol. *The Hospice Movement—A Better Way of Caring for the Dying*, New York, NY; Random House; 1978. Discusses the history and philosophy of the hospice movement and the kind of care the hospice has to offer.

NATIONAL CANCER INSTITUTE

NIH Publication No. 91-856
Revised August 1987
Reprinted December 1990